

Dementia: How should we care for the carers?

The campaign that all sections of society should become more 'dementia friendly' has clearly been gaining momentum in recent months. But the question remains: Are we paying enough attention to the needs of those who care day by day for loved-ones with dementia?

In a recent study in which Christians on Ageing participated, 53 churchgoing carers of various denominations, two-thirds of whom were female, agreed to answer questions about their experience caring for someone very close to them who was suffering from dementia. Their responses were heart-felt and deeply moving. They challenge churches and other agencies to consider much more carefully how best to address their needs in what is clearly an emotionally draining and very lonely role.

The unique challenge of caring for a loved one with dementia

Inevitably, since dementia occurs mostly amongst older people, the responsibility for care tends to fall on family members who are themselves older. 42 of the 53 respondents in this study were spouses, 8 were sons or daughters. None was less than 50 years old; most were in their 70s and 80s.

Since dementia is also a long, slow and progressive disease, often leading to unwelcome and unpredictable behavioural changes, the burden of care is relentless and tears at the carer's emotions. In this study, most respondents had been caring for their loved one for more than three years. For two the role had lasted more than 20 years. One daughter was still caring for her mother after 17 years.

It is clear from the responses that such caring presents a unique combination of challenges: Alongside the tiredness and emotional stress of non-stop caring over a long period of time, respondents highlighted three main factors: 1. Most significant were the changes in their relationship with their loved one, the lack of normal patterns of communication as the dementia became more pronounced. Some likened it to bereavement. They had lost the one in whom they confided most. 2. Many also mourned the loss of the social contact they had previously enjoyed, in church or elsewhere, as others found the dementia too difficult to deal with. 3. An additional factor was the patchy levels of understanding of their circumstances shown by medical, social and welfare services, and by church leaders. Cumulatively almost all the carers in this survey revealed significant degrees of loneliness, alongside grief, guilt, anger and, in a few cases, something close to clinical depression.

The diverse ways of experiencing a supportive faith

As regular churchgoers, this study's respondents brought to their caring role their faith as Christians. Almost all reported that, despite the all-encompassing pressures of their caring role, their faith had been supportive and had helped them to cope. However their responses revealed two quite distinct ways of expressing their relationship with God through faith: For just over half of these churchgoing carers, God was their rock. Their faith in God was 'static', 'unshakeable'. At the very least – despite all the pain they were experiencing – their faith 'survived'. For the rest, their faith was a journey in which they discovered how God was empowering them to cope. Their experience of God was 'dynamic'. 'God's grace was sufficient for them'. As a result they spoke of their faith being challenged, but also 'deepened'. Just one suggested that her faith had been 'lessened', commenting "It is hard to continue to believe in the power of prayer when you are dealing with an Alzheimer's sufferer."

By focusing on people who saw themselves as churchgoers, this study failed to reach those who, as

a result of their caring experience, had lost their faith and totally ceased churchgoing. In practice, for many carers in this study, continued churchgoing clearly became progressively more difficult over time, and for some the return to regular churchgoing was also proving quite difficult after their caring role had ceased. Their faith, however, clearly remained central in their lives.

Taking older people seriously – as individuals

Most respondents described some degree of support from their church, practical, pastoral or through prayer. However, many pleaded for a deeper understanding both of dementia and of what they were enduring as carers. In this study, what care-givers most prized was to be understood and empowered to cope with their responsibilities for as long as possible. Many respondents admitted that they were unwilling to ask for help. Caring for their loved one was their responsibility – even their privilege. Could they really trust anyone else to care for that person as lovingly as they did?

However, despite the widespread loneliness, several respondents spoke warmly of new and deeper friendships, both inside and outside the churches – friends who could empathise and in whom they could confide. Although being enabled to join a group with other dementia carers was recognised as welcome and valuable, the deepest experiences of emotional loneliness could only be offset by more intimate one to one relationships between individuals.

Some possible lessons for other churchgoers and church leaders

One clear message from this study is that churches and churchgoers need to be less wary of those suffering from dementia, and learn how to avoid stigmatising and insensitivity. This will be easier if, at the same time, we become more aware of the challenges facing the carer and of the individual needs and circumstances of the person with dementia.

Local churches can also plan explicitly to become more 'dementia friendly' – and realise that this is costly in terms of time and patience - and very demanding spiritually. Help is available to make this happen.

More generally this study reveals the unique qualities of an individual's faith journey over the course of a lifetime. Churches need to become better equipped to understand and respond to this - whatever may be that individual's personal circumstances and not least when they are older. It is unhelpful to try to impose prescriptive interpretations of what that faith journey 'ought' to be.

At a practical level, responses to this study show that many local churches need to be more disciplined about their pastoral care - and not leave it all to the minister! There is scope for more and deeper listening. Local church members should not give up on visiting those who are in danger of losing touch with their church because of the demands of their caring role.

However, more practical support and improved pastoral care, although necessary, may not be enough. Churches may have a crucial role in helping all carers, particularly those caring for loved ones with dementia, to find the new and deeper friendships that they need to offset the emotional loneliness of their caring role.

More specifically, some carers clearly face considerable difficulties, once their caring role has ceased, in returning to regular churchgoing after what has often been a long period of enforced absence. If other church members understand, they will be able to help.

Overall, churches need to recognise and respect what others outside their circle can do and are doing. All of us are challenged not to fear dementia, but rather to develop 'dementia-friendly'

values, policies and practices in all our dealings with persons with dementia and their carers.

A full analysis of the responses to this study is presented in two academic papers:

Jewell, A., Cole, J., Rolph J., & Rolph, P. (2016). *The faith of primary carers of persons with dementia*. *The Journal of Religion, Spirituality and Aging*, 28, 313-337.

doi:10.1080/15528030.2016.1193098

Jewell, A., Cole, J., Rolph J., & Rolph, P. (2017). *The loneliness of the long distance-carer: The experience of primary carers of loved-ones with dementia*. *Rural Theology*, 15, 2, 97-112. doi:

10.1080/14704994.2017.1375473

Useful resources for local churches

<https://www.livability.org.uk> - the web site of the Christian disabilities charity Livability.

<http://www.christiansonageing.org.uk> - the website of The Christian Council on Ageing (CCOA)

'*Growing Dementia-Friendly Churches*' by Gaynor Hammond – obtainable via the CCOA website, price £6 inclusive of p & p

<https://www.alzheimers.org.uk> – the website of Alzheimer's UK, where you can find details of your local branch of the Alzheimer's Society.

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